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ABSTRACT

This newsletter issue focuses on the specific concerns of many parents as their special child "ages out" of protected special education environments and moves into the adult world. It highlights the practical aspects of the transition years as well as the emotional components involved in "letting go." The newsletter's articles include "Aging Out...The Transition to Adulthood" by H. Carlton Smith, which emphasizes the importance in building a solid bridge between special education and adult programs and services, notes that planning for the future should begin before adolescence, outlines the parent's role in advocacy, and lists some sources of help. Several practical tips are then offered in the form of "do's" and "don'ts," such as seeking legal advice about guardianship and estate planning, and encouraging the special child to be as independent as possible. In "Letting Go: Samantha Grows Up," Linda Murphy describes her experience with a foster child with emotional disturbances and developmental disabilities. Samantha's progress in developing self-care skills and social skills led to her need for a community residence program where she formed friendships and found a balance of work and recreation, despite her foster mother's initial concerns. "When Parents 'Age Out,'" by George Popper, discusses common living arrangements for individuals with disabilities and parents' anxieties when they feel they are giving up their responsibilities as parents. (JDD)

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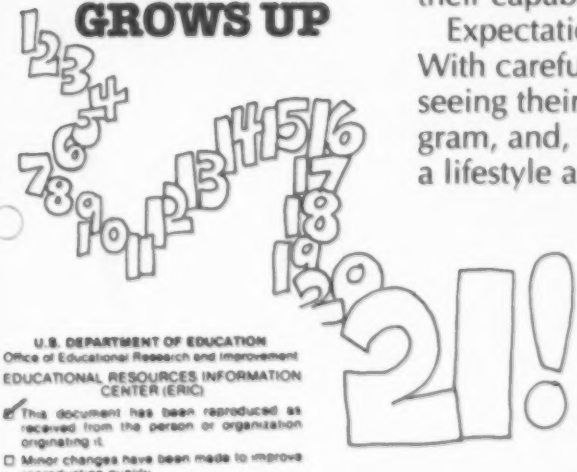
GETTING OLDER: THE SPECIAL CHILD GROWS UP



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In typical families, children develop, grow up, graduate from school, eventually find a job or vocation and, finally, move out of the family home into their own quarters. Most of the time the transition is smooth and parental expectations are fulfilled when the children they have reared demonstrate their capability and independence.

Expectations for a special child need not be different. With careful planning, special parents can look forward to seeing their disabled child graduate from school or a program, and, with certain modifications, lead as independent a lifestyle as possible.

In this issue we will focus on the specific concerns of many special parents as their special child "ages out" of the more protected special education environment and moves into the adult world. We are privileged to have as guest authors specialists in the area of adult services who will highlight the practical aspects of the transition years as well as the emotional components involved in "letting go."

Aging out . . . the transition to adulthood

by H. Carlton Smith, MSW, BCD

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Aging out is a process of change and transition involving a complex set of issues for young adults with disabilities and for their families. Growing up and into adulthood is particularly difficult for persons with developmental and emotional disabilities. Adolescence is a time of marked uncertainty and worry for special parents. "What will my child do when she can no longer attend school?" "What will happen when I am no longer able to provide care?" "Where will he live?" "Who will look after and protect her?" The goal of the aging out referral process is to facilitate a comfortable and successful transition from adolescence to adulthood by *building a solid bridge between special education and adult programs and services.*

When the transition is not coordinated, major gaps can occur, leaving the young special needs adult stranded between the two systems.

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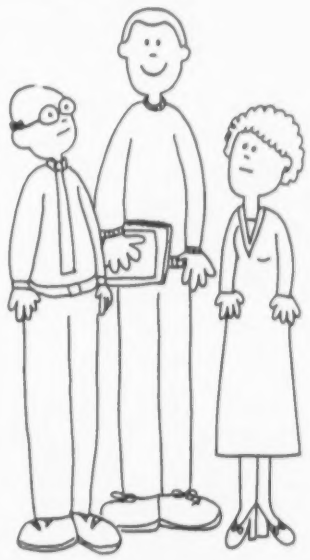
Planning for the future should begin early, even before adolescence. Try to visualize your child as an adult and make a list of the kinds of services and supervision that he may need. As parents, most of us anticipate less involvement in the lives of our children when they reach adulthood. But when a child has disabilities, parental expectations can take a nosedive. Responsibilities reach farther into the future. Parents must give thought to daytime programs and activities, alternatives to living at home, finances, health care and the all-important issue of *guardianship* to assure that necessary levels of care, support and direction are provided and that a good quality of life is maintained.

While there are federal regulations regarding the responsibilities of states to provide special education services and post-school services (adult education, vocational training, employment, independent living and community integration), there is wide variation from state to state in how the regulations are interpreted and implemented. The federal regulations stipulate that "a free appropriate public education (shall be) available for all handicapped children aged three to twenty-one." However, there are exceptions in certain states. As a result, eligibility for special education services ends at age 17 in Indiana, at 18 in Montana and at 19 in Maine. Florida limits special education to 13 years beginning with kindergarten. Twenty-three states extend eligibility to age 20, and 22 (including Washington, DC) go to age 21. West Virginia's eligibility continues to age 22, and Michigan's maximum age is 25. In most states, if students with disabilities receive a certificate of completion or meet other local criteria, eligibility for special education is terminated even if the student has not reached maximum age. In some states, services may continue to be provided after the maximum age if school districts serve non-disabled students to an older age.

The parent's role. Parents generally feel they are their child's best advocate. When the special education program is working well parents can relax a little. Adolescence and the approach of aging out, however, demand that parents become more active and vigilant in their collaboration with school personnel. They need to become joint architects in the designing of a workable transition plan by visiting adult services programs and making connections with the service providers of the not-too-distant future.



ABOUT SPECIAL PARENT/SPECIAL CHILD:

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The types of services most frequently required for young persons with disabilities who are leaving special education programs are vocational training, job placement and counseling. Some will need special transportation, residential care, financial supplementation and health care services. Adult services are designed to respond to lifelong needs, assure access to entitlements and promote independence, productivity and community integration.

Sources of help. For further information on aging out, you may want to contact your State Education Department, your State Office of Vocational Rehabilitation and your State Council on Children and Families. Also:

Association for Retarded Citizens
National Headquarters
P. O. Box 6190
Arlington, TX 76001

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Health Resources Center of the
American Council of Education
One Dupont Circle
Suite 800
Washington, DC 20036

Do's and don'ts

Do start early to teach your special child all aspects of daily self-care. The more self-sufficient your child becomes in dressing, grooming and personal hygiene, the greater his or her opportunity to be an accepted part of the community. If your child relies on you to do these things, he or she will be a burden to others in later years.

Do encourage your special child to be as independent as possible and to complete all assigned chores. Of course, it's easier and faster for you to do these things yourself; nevertheless, by instilling in your child responsibility for such tasks as room cleaning and table setting, you are providing him or her with lifelong good habits.

Don't wait until your special child is 21 or ages out of programs to find an agency to coordinate your youngster's older years since it often takes months or longer to find the right one. While your child is still of school age enlist the support of your child's school to find out where and how to seek help for future services.

Do be aware that in many areas there are sparse services for older disabled individuals and those programs or community residences available often have long waiting lists.

Do make sure as much as possible that your child's school program offers adequate preparation for his or her lifelong needs—look for career awareness, occupational education and prevocational training.

Do begin early to seek advice from an attorney or an appropriate agency about guardianship and estate planning. Although the laws vary from state to state, the older your child is the more complicated the process becomes.

ABOUT THE AUTHORS:

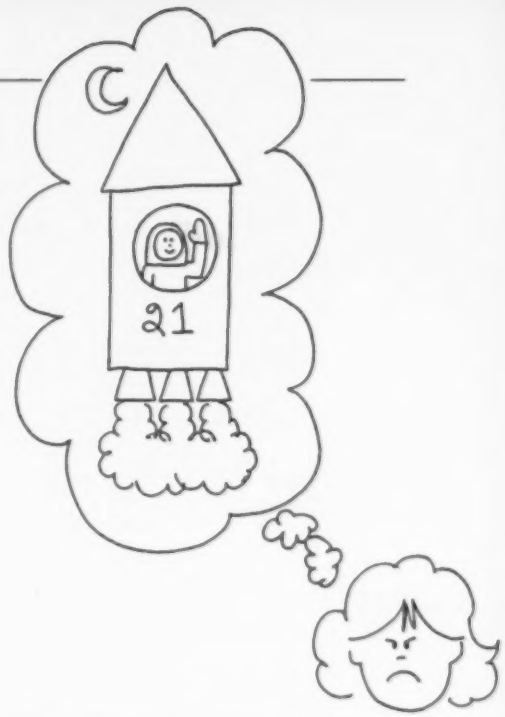
Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

LETTER FROM THE EDITOR

Letting go: Samantha grows up

Editor Linda Murphy would like to share with our readers the emotions and concerns she experienced when her developmentally disabled foster daughter was ready to leave home.



Samantha entered my life in 1973 when she was only three years old. The little blonde, brown-eyed toddler had been entered as a student in the school for handicapped children that I directed. Samantha had been labeled "too difficult to handle" and had been expelled from other programs for exceptional children. A dropout at age three, I thought! She could not talk, was not toilet trained and spent most of the day in raging, screaming temper tantrums. Nothing calmed her down or held her interest for long, and she had no response to either affection or discipline.

Samantha's records showed that she had been born to drug-addicted parents whose abuse and neglect were so extreme that she had been placed in a foster home. In those years little was known about the serious physiological and behavioral consequences of fetal drug addiction. She was diagnosed as "emotionally disturbed" and everyone expected that with proper care Samantha would surely recover completely.

This was not the case. Samantha was such a handful that her well-meaning foster family became overwhelmed. One day she arrived at school with her little suitcase packed and a social worker waiting outside to take her away to a state mental institution for long-term care. I was horrified; I knew from experience that this tiny toddler would spend the rest of her life wandering some back ward of a hospital with little to preserve her dignity or maintain her identity.

I took Samantha home—temporarily, I thought, until some more suitable place could be found for her. My work was cut out for me and to this day I thank goodness my husband and daughters were so sympathetic. No one got any sleep or peace. Samantha roamed all day and raged all night. When I tried to hug her she stiffened and stood like a statue. She screamed continuously and her tantrums went unabated despite my efforts.

All the professional advice I gave so freely to parents came home to roost—what a comeuppance! I found out firsthand that behavior modification methods are often too complicated to carry out in the home and that the tons of advice I was getting from everyone were well-intentioned but annoying. For the first time I began to understand what it really means to be the parent of a special child. I looked in the mirror at the dark circles under my eyes, and I realized that my household chores were undone and my professional responsibilities unraveling. At that point I mentally apologized to every special parent for my previous holier-than-thou recommendations!

I was so exhausted that I prayed Samantha would just sit in front of the TV, something I cautioned parents never to do, and I longed for some kind of doctor to prescribe a

magic pill for Samantha, something else I had warned parents against.

It was a very humbling experience. To my amazement and horror there were even more eye-openers in store. I found myself on the receiving end of irksome and demeaning treatment from professionals in the field. I'll never forget the anger and rage I felt over the superior attitudes of the professionals I consulted who discounted all my input because I had become simply "the mother." My background and years as a special education professional were ignored and I found, to my chagrin, that a parent garners little respect when the child has special needs. And because I had entered Samantha in another school to avoid a conflict of interest, I found myself besieged with well-meaning but unwanted advice from her teachers who prefaced every note with "Samantha won't" and ended them with "if only you would."

To this day I don't know how my family and I persisted. When the changes in Samantha did come, they came slowly, painfully. Gradually over the months and years

Samantha did improve. She began to respond to our patient love, and to the consistent structure and nurturing we gave her. She began to speak, haltingly; she became toilet trained; she slept a little bit better at night.

As Samantha grew older it became increasingly obvious that her difficulties went deeper than the initial diagnosis of "emotionally disturbed." Tragically, the fetal drug addiction had left Samantha with significant developmental disabilities. In Samantha's case this means her speech is somewhat garbled, she can't read or write and she requires supervision because of her lack of judgment. I reasoned that all these difficulties didn't mean Samantha couldn't be happy, look pretty or lead as functional a life as possible.

It took many years but I taught Samantha all the practical things she would need to become an accepted part of the community. I'm proud to say she can take total care of herself. She knows how to dress herself and take care of her personal hygiene. She can set and clear the table, prepare a simple meal, and takes pride in keeping her room clean and completing all her chores—doing laundry, putting away groceries. She keeps her hair shining and clean and takes special care of her beautifully-manicured hands. However, the most important thing that everyone notices about Samantha is that her eyes sparkle with an enthusiasm for life and people.

Although Samantha became a beloved family member, it was obvious as she grew older that family life could not continue to meet her adult needs.

When Samantha turned 21 I knew her school program would end. With few recreational facilities for the disabled in the area and her school friends dispersed, I realized

that Samantha would have limited opportunities to socialize. We live in a rural area with no public transportation so that even a simple excursion to buy an ice cream cone takes major planning. The nearest sheltered workshop is 30 miles round trip and I would have to drive. That meant I would have to orchestrate all Samantha's work and play activities in addition to holding down my demanding job. I felt exhausted and burnt out. Then I thought, "What kind of a life for Samantha is this anyway? She's worked hard at becoming functional and deserves more than a sheltered workshop and sitting home with me at night."

What did I want for an adult Samantha? I drew up what I call a Bill of Rights. I wanted Samantha to have the right to:

- become an accepted part of the community
- work at some useful vocation
- live in an attractive, home-like place
- enjoy a variety of recreational activities
- be accepted socially and have friends and peers
- be recognized for her unique attributes
- have the opportunity to be mentally stimulated and find self-expression
- have a continued relationship with her family who loves her.

When I looked carefully at Samantha's rights I realized that the type of life she needed is offered only in a community residence. She needed an adult program that would provide a home where she could form friendships and find a balance of work and recreation.

And I needed to let go. It took quite a while to find the right match but with the assistance of a kind social worker and an adult service agency, Samantha was accepted at a nearby community residence program.

I had many misgivings and fears. Would they take as good care of Samantha as I could? Would they be nice to her? Would they understand that she talks non-stop in a loud voice? Could they deal with her poor sleeping habits? Who would remember that sugar makes her "hyper" and that salad is her favorite food? I tossed and turned for nights, my thoughts racing from the ridiculous—"Who will match her outfits?"—to the serious—"Will she be properly supervised, protected from exploitation?"

When the time came for Samantha to leave I was too nervous to help her pack and had to ask friends for assistance. As I looked at the neatly folded clothes my heart pounded. It wasn't summer camp or a weekend away—it was forever.

Today Samantha is a proud member of an adult community residence. She lives in an attractive cottage on the grounds with six housemates. She goes to a sheltered workshop at the facility during the day, attends afternoon continuing education programs and fills her evenings and weekends with bowling, movies, parties, supervised dances, swimming, sports.

Last Friday night I managed to tear Samantha away from her activities to have dinner out. She proudly introduced me to two of her new friends and a staff member. She came with me happily enough, but midway through dinner she stopped, fork in the air, and said, "Mommy, I do not live with you anymore. Right? After dinner you are taking me back home, *my* home."

I felt angry, rejected, happy, sad and glad all at the same time. I also knew that my work was done.

PSYCHOLOGIST'S CORNER

When parents "age out"

by George Popper, Ph. D.

Special parents spend much time planning for when their special children grow out of educational programs. Equally important is what happens when the parents themselves "age out."

Intellectually, parents realize it is necessary to plan for their older special child, but sometimes unconsciously avoid doing anything about it because they fear it will be interpreted as lack of love or even abandonment. They are often beset with guilt over "letting go." Even when parents recognize their child's need for independence they worry about whether or not their child can make it on his own. When the time comes for their special child to live elsewhere many parents feel they are giving up their responsibilities as parents. Anxieties arise: "That place won't take care of my child the way I do." "I don't want my child to live with those people."

Fortunately, these concerns are unfounded in most cases. There have been many changes in the kinds of residential facilities available for individuals with special needs. The impersonal, hospital-like institution is largely a thing of the past. With help and accurate information parents can realize that there really are nice places for their older special child to receive life-long care and can make a decision that benefits both parent and child.

The type of living arrangement selected for the special individual usually depends on the level of care required and is based on diagnosis, special medical needs, and to what extent the individual can care for his own needs (personal hygiene, grooming, dressing, etc.)

The original determination can and does change with time. For example, an individual may start out needing a great deal of care and supervision but later learn to be more independent. She might then be eligible to move into a less supervised setting. The reverse is also possible. A capable individual might become more dependent due to age or illness, for instance.

Some of the more common living arrangements:

A **community residence (or CR)** can be a house, apartment, co-op or condo located in a residential community. The typical resident of the CR requires minimal supervision and care, and, in order to be eligible, must be able to care for all his personal needs. Usually the sponsoring state, county or private agency supplies a responsible staff person to live in the building or visit on a regular basis. The residents receive help with such things as budgeting, food preparation, transportation and bill paying. Day programming usually involves sheltered workshop kinds of employment. Medical care, counseling and recreation are often the responsibility of the operating agency.

As the name implies, **family care** happens in the home of a caring individual or family willing to provide a home-like setting for a disabled person. To become a family care provider, the individual must undergo an application process that evaluates their character, home, sincerity and ability to provide needed care. The referring agency (typically, governmental) pays the caregiver certain expenses and oversees their performance. Such arrangements are often sought by aged parents whose older or adult children have remained at home all their lives. These parents like the idea of having their child live in a family atmosphere. Age isn't always a factor—sometimes the disabled individual simply adapts better to such a setting.

An **intermediate care facility (ICF)** is reserved for individuals who are unable to live on their own and require supervision and help in areas such as personal care, language and adaptive functioning. Such a facility

operates under stringent regulations that require comprehensive treatment plans, ongoing programs and close supervision. A resident's progress is evaluated often to determine whether or not he continues to require this level of care. As with CRs, an ICF can be run by a private or governmental agency. In either case, the regulations and requirements are the same.

Supported living is an arrangement that specifically helps disabled individuals with marginal incomes. In this situation the individual's rent is based on her earnings. In most instances she is able to care for herself and often works in competitive types of employment.

Other types of living arrangements are:

- larger residential facilities with one or more cottages on the grounds.
- group homes that are extensions of an existing residential school.
- group homes that are sponsored by a sheltered workshop.

In any event, the need for all types of residential arrangements often exceeds availability—there can be long waiting lists. Priority is often determined by need (death or illness of the parent or caregiver, for instance). It is important to find out as soon as possible what is available and what the application procedures are. Lists of approved facilities are available from special education schools; the school psychologist or social worker is also a good resource.

Not everyone goes to a group home. In some families another family member—often a sibling—will take care of a disabled brother or sister. It should never be assumed that someone in the family will automatically take on this responsibility. These arrangements don't work out unless the details have been fully discussed and formalized with legal advice. It is important that nothing be assumed or left to chance.

Parents may not want their child to leave until the last possible minute or until a crisis occurs, such as a parent's death or incapacitating illness. However logical this may seem, the net effect can be disastrous. Special children of any age need time to adapt to change. They need to feel that moving to a group home or other facility is not a punishment but a natural progression in the growing up process. As with other children, parental visits, going home for special occasions, letters and phone calls from family will smooth the transition.

Letting go is part of being a parent. With the right attitude and planning, both child and parent can "age out" gracefully.

Illustrations by Leah Spring